

#### **November 2024 Newsletter**

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UK/EUROPEAN CENTRE OF EXCELLENCE FOR ME

## A Decade Developing the UK/European Centre of Excellence for ME

#### **IIMER's Vision for the UK/European Centre of Excellence for ME**



Despite facing funding limitations and institutional hurdles, the charity has laid a strong foundation for ME research, including supporting PhD students and the first post-doc(s) for ME, fully funding and facilitating the UK's only clinical trial for ME, and fostering European collaboration through networks such as EMERG and EMEA.

Located in one of Europe's most prominent research park, the Centre is uniquely positioned to lead ME research in the UK and Europe, but sustained investment is essential for it to realise its full potential.

With the retirement of director Professor Ian Charles from Quadram - having been leading Quadram since its formation - we now reflect on the progress made toward fulfilling this crucial need for patients over more than a decade.

Read of the essence of Invest in ME Research's decade-long effort to establish the Centre of Excellence for ME.



Read more



#### **New Quadram Director and CEO**

Professor Daniel Figeys becomes the new Director and Chief Executive Officer of Quadram Institute Bioscience.

Rad more on Professor Daniel Figeys at the Quadram site using the link below

Read more

#### **Conference Week 2025**

For 2025 we are extending International ME Conference Week to cover four days. The Young EMERG early career researcher workshop now will span two days.

The other events will be the EMERG meeting with USA researchers and #BRMEC14 Colloquium and the #IIMEC17 Clinicians Conference.



Read more



#### **EMEA News**

With our colleagues in the European ME Alliance we have been active in engaging with WHO Europe recently to represent myalgic encephalomyelitis in Europe, especially in connection with the recent 74th WHO Europre Regional Assemby (#RC74CPH) held in Copenhagen, Denmark. Below are some of the actions taken.



### Meeting with WHO Europe Director Dr Hans Kluge

EMEA arranged a meeting with Dr Hans Kluge, WHO Regional Director for Europe, to discuss ME and EMEA's plans and strategy. With representatives of <u>EMERG</u> and <u>Young EMERG</u> we demonstrated EMEA's work in creating collaborative environment between patients, researcher and clinicians.

Read more



# young EMERG A future for research into ME

#### Youth4Health

The Youth4Health network, WHO/Europe's firstever youth network, is a mechanism of the Youth4Health initiative, which connects youth organizations and young people to the work of WHO/Europe.

We were pleased to arrange for Johanna Rohrhofer from Young EMERG (and in EMERG member Dr Eva Untersmayr's group in Vienna) to be EMEA's representative.

Read more



Johanna gave her own reflections in the Young EMERG page here.

Read more



#### Statements at #RC74CPH

EMEA made several statements at the #RC74CPH meeting on different agenda items discussing -

- the State of Health in the WHO European Region;
- the European regional action framework for behavioural and cultural insights for equitable health, 2022–2027;
- the framework for resilient and sustainable health systems in the WHO European Region 2025–2030;
- Harnessing innovation for public health in the WHO European Region 2025–2030: preparing for a new strategy.

An overview of EMEA activities at the congress is available in the link here

Read more



## Another European Marathon for ME

Mike Harley has just completed another European marathon in support of Invest in ME Research's research and awareness.

The latest outstanding achievement was in the Podgorica Marathon in Montenegro.

Read Mike's race report here -

https://www.mikeseumarathons.eu/montenegro.ht ml

Mike's JustGiving page is -

#### www.justgiving.com/mikeseumarathons

10 years of raising awareness and vital funds for research - yet Mike is even now planning on running marathons next year in Belfast in May North Macedonia in October.

If there is anyone in those countries who would like to make contact then please contact us



#### **Christmas Cards Available from IIMER**



Our Christmas cards are now available to order. This year we have tried to make it a little easier for our supporters.

So our cards are offered in packs of 10 at the price of £2 per pack - and this includes UK mainland delivery (email the charity for delivery outside of UK)

Order using the link below.

We also have Christmas stickers available.

Read more



## From Broken Wings to Clearer Skies

The last thing that people with ME, or their families and carers, need is added stress or an environment that many now consider toxic and unproductive. For many some social media experiences are less than happy these days.

We have been on Bluesky Social for some time.

Read more



#### Mygivingcircle

The MyGivingCircle grant awards are still going. Thanks to the wonderful support the charity has been getting and the efforts of our supporters to publicise this. Any funds received go toward the research projects.

The link is here and only needs an online vote

#### **Movement for Good**



12 Days of Giving is the final phase of Movement for Good 2024. In December, they are giving 120 charities £1,000 each over 12 days. The first draw takes place on December 5th - the last on December 20th with 10 charities drawn every week day. Nominations are open until December 19th 2024.

We would really appreciate nominations for Invest in ME Research.

<u>Use this link to make a simple online vote.</u> Thank you



Invest in ME Research is a charity of volunteers - but working continuously to improve the research, treatment and perception of myalgic encephalomyelitis (ME). We welcome support to continue our efforts to advance research and European and international collaboration into this disease.



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